

4. Ways to Conduct Community Outreach and Education

4

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What You Can Do

- Find opportunities and develop a strategy to speak about clinical trials and/or:
 - Present NCI slide programs or the awareness video
“Cancer Trials...Because Lives Depend on It”
 - Distribute educational materials such as those in this series:
 - At meetings or events
 - Through doctors’ offices
 - Through a booth for local research institution(s) at events
- Write articles for newsletters; post articles on Web sites
- Host an information session or community forum on clinical trials
- Form a clinical trial advocacy coalition

Why?

- To provide information to people about cancer clinical trials before they are faced with a cancer diagnosis
- To provide information about a specific cancer trial to members of your community
- To provide people with the tools they need to find out about trials in your community
- To educate interested members of the public about the importance of cancer clinical trials
- To help debunk myths about clinical trials in the community
- To develop a community strategy for clinical trial outreach

Introduction

This section provides ideas for educating your community about clinical trials. Whether you use personal contacts, community organizations, or health-related organizations, remember that combining strategies to get clinical trial messages out to your community will make your outreach more successful. Using different ways to get out critical messages about clinical trials increases the chance that people in your community will absorb and remember them.

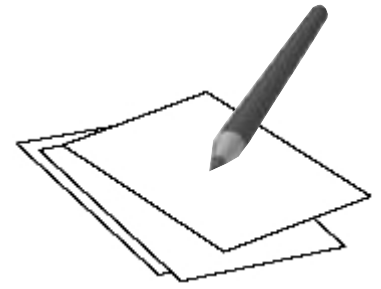
See the *NCI Trainer's Guide for Cancer Education* for ways to teach others about these issues. Information about ordering can be found at the front of this guide.

Education and Outreach in Action

A chapter of a local cancer advocacy organization had been trained about clinical trials. Several members organized a community forum, inviting the local researchers on a breast cancer prevention trial to speak. They also invited several women who considered participating in the trial. More than 75 people attended the forum at the local YMCA.

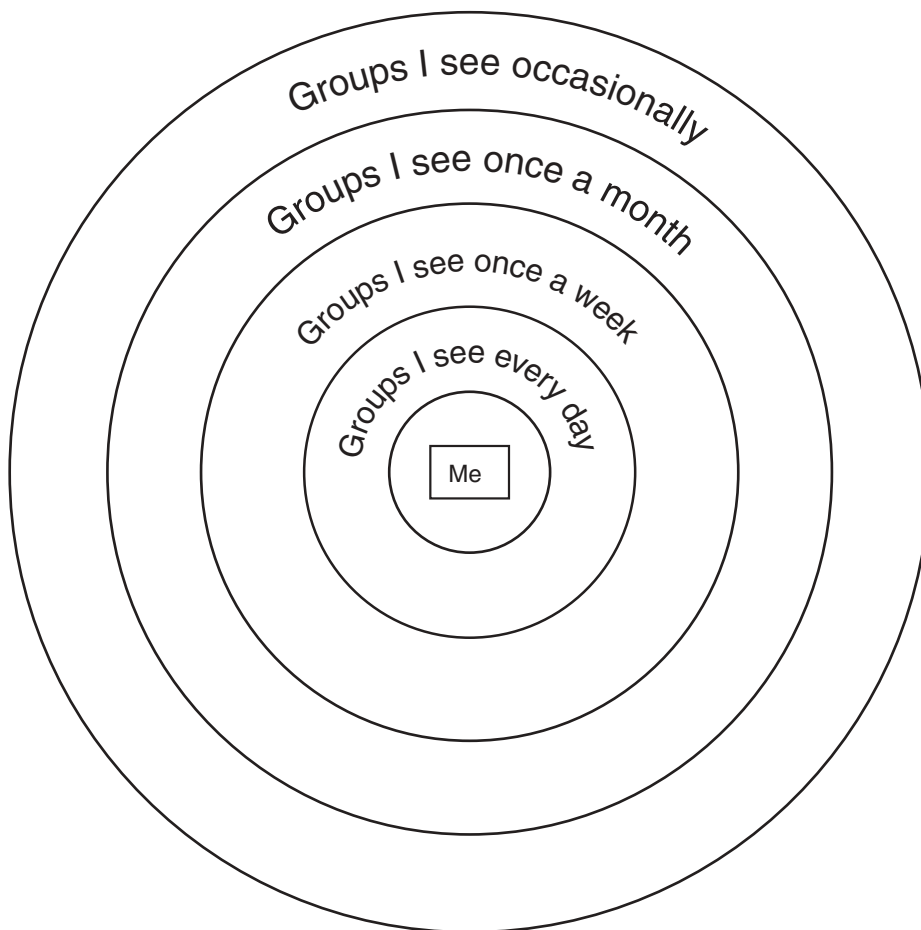
A local cancer support group has a Web site and a quarterly newsletter. The group's education committee copied the articles included here and put them on its Web site and in its newsletter. At the next meeting, the group decided that all of its members should learn about clinical trials.

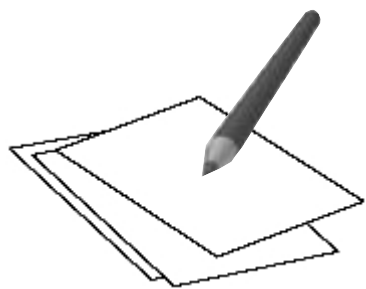
1. Get Started—Circle of Connections with Groups



Everyone has connections with different groups in his or her community. Some people represent a specific organization. Others may have connections with many different community groups. As you think about the importance of clinical trials, think about where and how you can become a clinical trial resource to these groups. How can you help engage the organization in this issue?

In the circles below, write down at least five groups or organizations you feel you can educate. The groups don't need to be cancer-related, but should have a health focus. Keep these groups in mind as you complete this section.





2. Expand Your Organization's "Community"

It is important to think broadly about other organizations with which you can partner, whether you are part of a group or organization that already has a clinical trial agenda, or if you want your group to develop one.

A given geographical area includes many "communities." In the following table, write down the organizations you identified on the previous page.

Then, think about:

- Reaching out to other groups in your community who are likely to share clinical trial priorities
- Partnering with organizations with which you haven't yet worked
- Contacting people who can put you in touch with key leaders of these groups

The pages that follow will help you prioritize your outreach efforts. It will be important to consider balancing your efforts between groups that are easy to reach with others that will take more effort.

For more information on working with different ethnic/minority groups, see section 1.

Organization Contact Worksheet

Organization Type	Examples in My Community	Contact People in Community
Advocacy organizations		
African American, Asian American, Latino, and Native American-based organizations		
Cancer-oriented nonprofit organizations		
Cancer support groups		
CDC Breast and Cervical Cancer Early Detection Program coalition members (hint: check with your State health department)		
Chambers of commerce		
Community cancer centers		
Community health centers/ public health clinics		
Employee associations of large companies		
Health care professional associations (doctors, nurses, social workers, health educators, etc.)		
Hospital education departments		
Hospitals and research institutions		
Housing organizations		
Labor union locals		
Lesbian/gay organizations		
Men's organizations		
Religious organizations/houses of worship		
Senior citizens' organizations		
Service organizations, such as Rotary, Lions, Kiwanis, Jaycees, Junior League		
State cancer control committees		
Veterans' groups		
Women's organizations		

3. Prioritize—Develop a Strategy and Philosophy

As you begin to consider different outreach and education activities, you'll need to think strategically. Answering the following questions can help ensure the success of your outreach and education efforts.

Setting Objectives

- Why should we get involved with clinical trial outreach and education?
- What is the problem we want to address? (Be realistic!)
- What is the goal or expected outcome of our efforts?

Conducting Research

- Is our clinical trial advocacy goal clear and realistically attainable?
- Who are our primary allies?
- Have similar clinical trial education efforts been attempted in the past, either in our community or elsewhere? What lessons can be learned from them?
- What is the most compelling information that we can use to make our case? (Think about your targets as you answer this question.)

Considering “Targets”

In figuring out who your audience is, keep in mind that the “general public” is not specific enough to be a target audience. Ask:

- Who are the key targets for our efforts?
- Are there key people who can help our efforts in reaching these audiences? Leaders of professional organizations? Community leaders?
- Who is our “community,” and how can it be expanded? (Use your sheet on page 63.)

Considering a Philosophy

The questions that follow represent a simplified framework for outreach and education efforts that could be large and complex. The more complete your initial answers, the more likely it is that your efforts will proceed smoothly and successfully. Consider the following:

- What are the most appropriate ways for our community to learn about clinical trials?
- Do we want to simply inform people? Or do we want to influence attitudes and change behavior?
- Which channels best fit our message about clinical trials?
- What avenues are most likely to be credible to and accessible by our community or our “targets”? Meetings? Trainings? The media? Mail? Networks of contacts? Doctors’ offices? Community races?
- How can we complement existing cancer awareness activities, such as national theme months (e.g., October is Breast Cancer Awareness Month), local health fairs, and local hospital events, in our efforts?
- Who are our best spokespeople? How can we use community leaders in our outreach efforts?
- Does timing play an important role in some of our planned activities? Will other pending issues claim our targets’ attention?

If you are not from the population(s) you seek to work with, it is critical that you or your organization develop partnerships with organizations from those communities.

Keep in mind that different communities find different information sources credible and may respond better to certain outreach strategies. Forming partnerships with other organizations, rather than simply asking them to join existing efforts, can help ensure that your educational and outreach efforts will be successful.

4. Use NCI Audiovisual Materials to Make Presentations

You can present clear information about clinical trials to local groups by using one of NCI's three slide programs or the awareness video, "Cancer Trials...Because Lives Depend on It." Most of these materials are geared to the general public and feature interactive discussion guides or talking points. By showing these materials at a meeting or as part of a larger program, you can generate discussion on the importance of clinical trials in your community. See ordering information at the front of this guide.

5. Distribute Materials

Distributing materials is more than putting brochures out on a display table. Consider the following ideas.

At Events or Meetings

- At meetings in which everyone receives a packet of material, target educational materials by inserting a cover letter signed by an influential person in your community.
- At events, such as health fairs or lectures, place materials out on a table. Offer candy or water and cups. Instead of standing behind a table, think about standing in front, to make your table look more inviting. Greet people warmly.

Through Doctors' Offices

Partnerships may be developed with health care providers to educate their patients about clinical trials. Primary care providers may be willing to discuss prevention trials with their healthy patients. Some may be willing to send out materials to their patients.

Through a Booth for Local Research Institution(s) at Community Events

Often local institutions will be eager to host a booth to discuss the clinical trials they offer. These booths can also enhance community awareness around clinical trials.

6. Write Articles for Local Newsletters and Web Sites

Local organizations' Web sites, listservs, and newsletters can be targeted and effective ways to reach community members. Use the sample newsletter articles provided here to submit to organizational newsletters and Web sites.

Your organizations' own publications are one likely avenue. Other organizations may also be eager to publish information. Review each organization's media to understand better what they are likely to publish:

- Who is the target audience?
- What types of articles are currently available?
- Who can help get this article published/online?

The Pros and Cons of Using Newsletters

Pros

- Newsletters are tools for intra- or interorganization communication.
- Newsletters help show how organized your group is and help keep your members and colleagues current on your activities.
- Newsletters have a very broad audience.

Cons

- Newsletters take time, money, and skill to produce.
- Newsletters are not well suited for publishing late-breaking news.

Sample Newsletter Article 1

Newsletter

Clinical Trials: An Important Part of Our Mission

[Insert how clinical trials relate to your organization's mission, and why you are getting involved with clinical trial outreach and education.]

Just as there are misconceptions about cancer screening tests, there are misconceptions about clinical trials. When people think about clinical trials, many imagine “guinea pigs”—participants getting inferior treatment or a sugar pill (placebo) instead of actual medical treatment. Many people also think that clinical trials are for only the people who have no other treatment options available to them. This article provides an overview of why clinical trials are important, what they do, and why they are a critical part of our work.

Why Clinical Trials Are Important

Clinical trials are a critical part of the research process. Clinical trials help to translate basic scientific research into new treatments. By evaluating the results of these trials, researchers are finding better treatments for cancer and ways to prevent cancer. The more people that participate in clinical trials, the faster we can answer the critical

research questions that will lead us to better treatment and prevention options for all cancers. Doctors will never know the true effectiveness of a cancer treatment, or a way to prevent cancer, unless they are able to involve more people in clinical trials. And, research shows that few of us really understand what clinical trials are.

Cancer Treatment Trials

Most cancer clinical trials are treatment studies. These clinical trials involve people who have cancer. These studies try to answer specific questions about and evaluate the effectiveness of a new treatment or a new way of using an old treatment. Treatment trials seek to find out:

- What new treatment approaches can help people who have cancer?
- What is the most effective treatment for people who have cancer?

In most cancer treatment trials, in which one treatment is compared with another, people receive either the most advanced and accepted treatment for the kind of cancer they have—known as the “standard” treatment—or a new treatment that

has shown promise of being at least as beneficial as the standard treatment, if not better. People in these trials do not receive a placebo for their treatment.

In the past, clinical trials were sometimes seen as a last resort for people who had no other treatment choices. Today, many people with cancer, even those whose cancers have not spread, get their first treatment in a clinical trial. All people with cancer can benefit from learning about all their treatment options, which include participating in appropriate clinical trials.

Cancer Prevention Trials

Unlike treatment trials, cancer prevention clinical trials are studies involving healthy people who are at high risk for developing cancer. These studies try to answer specific questions about and evaluate the effectiveness of ways to reduce the risk of cancer. Prevention trials seek to find out:

What approaches can prevent a specific type of cancer from developing in people who have not previously had cancer?

Risks and Benefits

Clinical trials have both benefits and risks—and they are not the right option for everyone.

Possible Benefits

- Participants have an opportunity to make a valuable contribution to cancer research.
- Participants have access to new anticancer approaches before they are widely available.

Possible Risks

- New approaches may have side effects or risks that are unknown.
- Even if a new treatment under study has benefits, it may not work for every participant.
- Participants may have to pay for the costs of travel, childcare, lost work hours, and meals.

[Discuss your community's education and outreach efforts.]

How to Learn More about Clinical Trials

Call NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237) and ask for a customized search of the PDQ database, which provides information on current studies. Ask for the following pamphlets, which are available in English and Spanish:

- "Taking Part in Clinical Trials: What Cancer Patients Need To Know"
- "Taking Part in Clinical Trials: Cancer Prevention Studies"
- "If You Have Cancer... What You Should Know about Clinical Trials" (easy to read)

Or you can visit the clinical trials area of the NCI Web site at www.cancer.gov. ■

Sample Newsletter Article 2

Newsletter

Key Facts about Cancer Clinical Trials

Cancer clinical trials are research studies in which people help doctors find ways to improve health and cancer care. Each study tries to answer scientific questions and find better ways to prevent, diagnose, or treat cancer. These studies are the final step in the process of developing new drugs and other means to fight disease. Clinical trials are the way we make progress against cancer.

Understanding that Cancer Affects All of Us

- Cancer affects us all—whether we have it, care about someone who does, or worry about getting it in the future.
- Consider the impact of cancer in the United States* in 2001:
 - Each year, about 553,400 people are expected to die of cancer—more than 1,500 people a day.
 - Cancer is the second leading cause of death, exceeded only by heart disease.
 - 1 of 4 deaths is from cancer.
- About 1,268,000 new cancer cases are expected to be diagnosed each year.
- Research has shown that there are many differences in who develops

cancer and who dies from cancer among men and women, and among people of different races, ethnicities, and socioeconomic backgrounds. Differences in cancer screening and treatment have also been documented for people of different ages, incomes, educational, and racial/ethnic backgrounds.

Understanding What Clinical Trials Do to Fight Cancer

- Clinical trials are a critical part of the research process. Clinical trials help to translate basic scientific research into practical treatments. By evaluating the results of these trials, we can find better treatments for cancer and ways to prevent cancer.
- Clinical trials contribute to knowledge and progress against cancer. Many of today's most effective cancer treatments are based on previous study results. Because of progress made through clinical trials, many people treated for cancer are now living longer.
- The more people that participate in clinical trials, the faster we can answer the critical research questions that will lead us to better treatment and prevention options for all cancers. We will never know

the true effectiveness of a cancer treatment, or a way to prevent cancer, unless we are able to involve more people in clinical trials.

- In the past, clinical trials were sometimes seen as a last resort for people who had no other treatment choices. Today, many people with cancer, even those whose cancers have not spread, get their first treatment in a clinical trial.

Understanding How Few People with Cancer Take Part in Clinical Trials

- Enormous improvements in treating childhood cancers have come about as the direct result of clinical trials; more than 60 percent of U.S. children with cancer participate in clinical trials. In 2000, more than 70 percent of children with cancer are alive 5 years after diagnosis, compared with only 55 percent in the mid-1970s.
- In contrast, only 3 percent of U.S. adults with cancer participate in clinical trials—far fewer than the number needed to answer the most pressing cancer questions quickly.

- According to a survey in 2000, most people with cancer were either unaware or unsure that participation in clinical trials was an option for their treatment, and most of them said they would have been willing to enroll had they known it was possible.

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*American Cancer Society (2001). Cancer Facts and Figures.

7. Host an Information Session/Community Forum—A Step-by-Step Planning Guide

Many organizations choose to hold community events on clinical trials, which can be an effective way to reach community members. Careful planning is required to ensure your event is a success.

Step 1. Establish a Community Forum Organizing Committee, If You Are Planning a Large Event

The organizing committee could include members from your education committee or your board. You will need to determine a budget for the project that includes costs of meeting room rental, printing flyers or invitations, advertisements, and postage.

Involve other parts of your community—such as the leadership of other nonprofit or advocacy organizations—in the planning process.

The entire committee may need to meet only a few times to discuss presentation goals and outreach strategies. A timeline and specific “job responsibilities” can be discussed at the first meeting.

Step 2. To Focus Your Information Session, Clarify Your Goals

It is important to answer the following question before beginning to plan the event. Potential answers are provided here, but you should answer this question for yourself: *What is the goal in hosting this forum?*

You should aim for goals that are clearly expressible. Try not to be overly ambitious for one community presentation. Getting community leaders involved with clinical trials and educating community members about clinical trials should be among your primary goals.

Specific goals of the meeting/forum might be to:

- Provide information about a specific cancer trial to members of your community.

- Develop a community strategy for clinical trial outreach.
- Provide people with the tools they need to find out about trials in your community.
- Educate the public about the importance of cancer clinical trials.
- Help debunk myths about clinical trials.
- Make clinical trial information more accessible.
- Share information with local organizations, compare strategies, and unify positions on common issues.
- Encourage people to inform others about clinical trials.
- Begin to build links between local researchers with community members.

Step 3. Determine Your Target Audience

Think about who and why. Develop a target audience list. Be sure to involve community leaders.

Possible audiences include those listed on page 63: “Expanding Your Organization’s Community.”

For ideas in reaching cancer-related organizations in your community, use the following sources from the National Cancer Institute’s Cancer Information Service:

- “Cancer Facts: National Organizations That Offer Services to People with Cancer and Their Families” is available on the Web at www.cancer.gov/cis or by calling 1-800-4-CANCER. This listing features dozens of organizations, many of which have local chapters, members, or affiliates.
- Your regional Partnership Program manager (who can be reached at 1-800-4-CANCER) can provide a list of local organizations that may have an interest in participating in your educational efforts.

Step 4. Choose an Interesting Theme with a Catchy Title

The theme should combine your organization's goals with what you believe your target audience will find of interest. Some ideas are given here.

General Information on Clinical Trials

- What are clinical trials and why should we care about them?
- How are cancer prevention clinical trials different from other studies?
- What are the myths and facts about clinical trials?
- How are people protected in clinical trials?
- How does cancer research in our community address the concerns of people living with the disease?
- How can someone decide whether to participate in a clinical trial?
- What are the barriers to accessing clinical trials?

Specific Information on a Particular Trial

Provide information about a specific prevention or treatment trial that may be having problems accruing patients. The presentation can explain why it is important, including the risks and benefits. If possible, give the locations of the trial sites in your area.

Community Advocacy for Clinical Trials

- How can we help reduce the barriers to participation in clinical trials in our community?
- How can we advocate for third-party payers to cover clinical trial costs?
- How can we develop a community strategy for clinical trial outreach?
- How can we make clinical trial information accessible to those who need it in our community?
- How can we find ways to help people understand that clinical trials can be a viable treatment option?
- How can people newly diagnosed with cancer learn about clinical trials in the community?

Step 5. Choose the Forum Speaker(s), Format, and Date

Be sure to invite people who:

- Can speak to lay audiences without using a lot of technical information
- Have a good rapport with the audience
- Live in the area
- Present information that people can use

Tip

When planning a special event, keep in mind that many audiences are unfamiliar with scientific terms. Strive to make information presented at your special event easy to understand and creative.

For speaker ideas, contact principal investigators from the list of cancer trials in your community. (See page 107 for more information.) You can also contact your local cancer center, hospital, or medical center or the Cancer Information Service for help in finding speakers who will appeal to your audience.

Choose your date carefully. Make sure it is a time when most people can attend and that it doesn't conflict with another large community event or a holiday.

Tip

If your speakers are your big draw, you may want to offer several dates to accommodate their schedules before the date is confirmed.

Step 6. Decide on the Best Way to Inform the Target Audience about the Event

Your message should reflect the theme you've chosen. The cost, timing, and available person-power will affect the method you choose to publicize your event. Consider the following methods:

- Mailing invitations or flyers to organizational mailing lists
- E-mailing event announcements to organizations and individuals
- Posting on Web sites
- Advertising in local media, such as radio stations and newspapers
- Distributing flyers or posters in the community
- Contacting cancer centers, hospitals, support groups, and patient groups

Step 7. Obtain Educational Materials

At the event, provide participants with handouts on the benefits of cancer research (e.g., handouts in this series). Encourage them to share information with friends, relatives, and other people in their lives.

Step 8. Arrange for a Location

Choose a location that is accessible by various modes of transportation.

Step 9. Select an Event Format

Research has shown that adults strongly prefer interactive delivery methods, which allow them to learn new information by:

- Seeing
- Experiencing
- Discussing

Many scientists do not use these delivery methods, but you can encourage their use to promote effective discussions in community presentations. Remember that you want to advocate for people to take action after they leave the forum.

Be creative in your format. Adults often gain the most out of presentations by figuring out how they can apply the information

in their lives immediately. Possible formats include:

- **Single speaker format.** An easy option is a presentation that includes an expert speaking and answering questions about cancer research. For example, a doctor, research scientist, or outreach coordinator who is involved in a cancer clinical trial could speak about the work he or she is doing in the community.
- **Panel discussion.** A small group of experts (usually between three and five) discuss a topic among themselves in front of an audience. Panel participants don't make formal presentations. They exchange ideas through conversation. Panels can expose the audience to different points of view about a single subject. Audience members ask questions or comment on the subject after a panel discussion. Usually, a time limit is set for each question and for the entire question-and-answer period. Cancer trial panels might include:
 - Survivors who reflect the diversity of your community who can discuss their decisions about trial participation (survivors who are community leaders or otherwise well known in your community might be of particular interest to your target audience)
 - Cancer researchers who can discuss their work
 - Survivors and scientists who can discuss both the personal decisions and the science behind trials
- **Symposium.** A small number of experts make short presentations in succession. Presentations usually range from 5 to 15 minutes each.
- **Open forum.** Members of the audience may participate at any time during the meeting.
- **Colloquy.** During a panel discussion, audience members may be invited to comment or ask questions if a panel member or the chair perceives a need to clarify points, raise an issue, or ensure that a misperception doesn't stand. Any interruptions of the panel discussion must focus on the point at hand. When the matter has been resolved, the organized discussion among panel members resumes.

- **Buzz session.** The audience is divided into groups of six to eight people for discussion of questions posed by the leader. One person from each group may be asked to summarize the group's discussion and report to the entire audience.
- **Audience reaction team.** Three to five members of the audience are pre-selected to respond to a presentation by offering a brief summary and interpretation of information presented. This discussion method can be used effectively in large-group settings and when time is limited.
- **Question period.** Members of the audience have an opportunity to ask questions of a presenter once the formal presentation is completed. Usually, a time limit is set for each question and for the entire question-and-answer period.
- **Workshop.** A small group of people (up to 25) with a common interest meet to study, research, and discuss a specific subject or to enhance their individual knowledge and proficiency.
- **Seminar.** A group of people who are studying a specific subject meet for a discussion led by a recognized authority.

Tip

No matter what format you choose, make sure you allow plenty of time for questions and answers.

Working with Presenters

Preparation

- Interview potential presenters in advance! You need to assess a presenter's ability to discuss areas related to clinical trials, and any personal experience he or she may have. Ask potential presenters about their willingness to participate in an event. Provide information about the date, time, and focus of the event. Discuss any concerns about anonymity (e.g., picture-taking or media presence).
- Budget for honoraria and expenses. Whenever possible, pay presenters an honorarium and offer food, mileage, parking, and childcare reimbursement. If possible, plan to pay in cash the day of the workshop (and get a signed receipt).
- Send a confirmation letter. Make sure it includes date, time, and focus of the event, details about honorarium, travel to the site, parking, and a telephone number of a contact person at the training site.
- Call presenters 3 to 7 days before the event. Ask whether they have questions. Discuss plans for focusing on specific issues. Ask how they wish to be introduced. It may be easiest for presenters to introduce themselves, so they can disclose as much or as little identifying information as they like.
- Obtain a facilitator/moderator. The facilitator's role is critical to the event's success. A facilitator manages the discussion. Presenters need support from the facilitator, who should:
 - Assure them that they can refuse to respond to any question for any reason
 - Monitor time carefully and gently, so everyone gets a chance to speak
 - Help with questions and answers
 - Be available after the event to assist presenters and offer feedback
- Arrange to meet with all panelists before the presentation. This will help alleviate their anxiety and provide a chance to discuss any last-minute issues.
- Review the format for the panel. Look at time allowed for each presentation and when/how questions will be taken from the audience.

At the Event

- Explain why you are holding a panel discussion. Hint: Distribute an information sheet listing panelists and their affiliations. Then you won't have to spend a lot of time on introductions.
- Review the ground rules. Tell the audience how much time each panelist will have to speak. Explain when audience members will be able to ask questions or offer comments.
- Show courtesy and respect for differing points of view.
- Pay careful attention to respecting limits on time.
- Summarize in the last 5 minutes. This is important, even if you have to say, "This discussion left many of us with more questions than answers!"

Plan Your Community Events—A Sample Timeline

Whether you plan to host a forum or run a video presentation, this checklist can help you plan.

6-8 Weeks in Advance

- ☐ Identify target audience
- ☐ Identify and reserve site for meeting and ensure video equipment is available—will it be a part of a regular organizational meeting, a visit to someone's home, a special event?

4 Weeks in Advance

- ☐ Refine target audience
- ☐ Review audience needs
- ☐ Develop and send e-mail/flyer
- ☐ Order supplies, copies, and educational materials
- ☐ Confirm site reservation, video equipment

2 Weeks in Advance

- ☐ Check in with onsite coordinator on number of participants and any changes anticipated
- ☐ Get flip charts and markers (if needed)
- ☐ Get nametags (if needed)
- ☐ Organize handouts
- ☐ Make sure any videotape works/CD-ROM works

1 Week in Advance

- ☐ Prepare supplies and materials for presentation, place in boxes

Day of Session

- ☐ Arrive at least 30 minutes before scheduled start time
- ☐ Check set-up and comfort of room
- ☐ Place welcome and directional signs in the facility
- ☐ Make sure you know how to work video equipment

1 Week after Session

- ☐ Send thank-you letter to on-site coordinator, participants

8. Form an Advocacy Coalition

A coalition is a group of organizations and individuals working together for a common purpose. There are two types of coalitions or partnerships:

1. Single-issue or event coalitions need to agree only on one particular issue or event. The coalition dissolves when the issue is resolved or the event takes place.
2. Multi-issue coalitions focus on a set of related issues, such as clinical trial access, health care for all, or quality of cancer care. This more permanent type of coalition recognizes the value of mobilizing together for action over a longer time. To be effective, a multi-issue coalition should set a date for its work to be completed. The coalition can always be reorganized if needed.

Why Form an Advocacy Coalition?

- To build important links among community-based organizations and clinical trial sites
- To share information with local organizations, compare strategies, and unify positions on common issues
- To help:
 - Set priorities for action or funding
 - Carry out an educational or outreach plan
 - Broaden the development of new constituencies

The Value of a Coalition or Partnership

Coalition building is needed when one organization recognizes that it alone does not have the capability or people-power to have a real impact on an issue.

Clinical trial outreach is complex. Think of innovative ways to reach underserved communities with clinical trial information. You can be a catalyst for building important links among community-based organizations and clinical trial sites.

Getting Started

Analyze Your Organization

Analyze your interests before asking other groups to join in your efforts. Ask yourself:

- What can be gained from joining with others?
- Will the advantages outweigh the disadvantages?
- How can we best communicate the demands of other groups to our organization?

Forming an Advocacy Coalition—A Planning Guide

Step 1. Establish a Partnership Organizing Committee

The committee can be made up of leaders in your organization. The committee manages the formation of the entire partnership. Specific job responsibilities can be divided at the first meeting.

Step 2. With the Group, Clarify Your Organization's Interest in Developing a Community Partnership

- Why do you want to advocate for access to clinical trials? Why is it important?
- Which issues, questions, and behaviors around clinical trials are of particular interest to you, and why? Do you need more information on these topics?
- What don't you know about these issues, questions, and behaviors around clinical trials? What questions do you need to have answered?
- What outside resources can you tap to help you understand the issues?

Identifying what you know about an issue also helps highlight what you don't know—issues you can ask about when you get other organizations involved.

Step 3. Identify Current Needs and Resources

When you start looking closely at clinical trial issues in your community, you need detailed information about the needs of individuals and the organizations that serve them, as well as the resources that your community has available to solve those needs.

Needs can be defined as the gap between what a situation is and what it should be. A need can be felt by an individual, a group, or an entire community. It can be as concrete as the need for more clinical trials or as abstract as improved community understanding of clinical trials. Examining needs can help you discover what is lacking, and points you in the direction of future improvement.

Resources, or assets, can be used to improve quality of life. They can be anything from people to places to organizations. Everyone is an asset, and everyone has assets that can be used for community building.

Identifying current needs and resources can help you:

- Understand the environment where you'll be working.
- Know how the community feels about an issue and what members think needs to be done about it. Getting the opinions of community members, identifying both the resources and limitations of your area, will give you a holistic view of the issue.
- Make decisions about priorities for program or system improvement. Once you assess the community, it is much easier to make improvements that community members will notice and benefit from.

This needs assessment process will be an ongoing part of forming your coalition.

Step 4. Start with What You Know

After choosing an issue to focus on, you may find possible solutions. Ask yourself:

- What do we already know about the needs and resources for clinical trials in our community?
- Has anyone else researched this topic in our community? Can we rely on this other work to give us insight and answers?
- Are there experts in the community who can answer some questions before we get started in forming the coalition? (Their input may narrow the remaining questions you need to ask other community members.)

Step 5. Identify the Key Organizations with Which You May Be Working

Develop a list of organizations likely to want to participate in the project. Be sure to include the institutions conducting clinical research in your community. Possible participants may include those listed on page 63.

Remember that this project presents an opportunity for you to build important links among people with cancer, researchers, doctors, and advocates.

Step 6. Determine What You Will Ask of Groups Who Join Your Efforts

For example, each organization must be committed to:

- Addressing clinical trial barriers in the community
- Coordinating to solve the problem, not just to gain public recognition
- The right of every other organization to be involved
- Open communication

Step 7. Write a Letter or E-mail Inviting Organizations to a “Brainstorming” and Planning Session

The goal of this meeting is to figure out how community groups can address local concerns associated with clinical trials. This initiative may focus on collaboration among the groups. Keep in mind that priorities may be different among the groups. This could be an open meeting for discussion among interested parties. Publicize the event through the media and at meetings.

Step 8. To Followup with All Participating Organizations, Provide an Outline of Your Plans

Ongoing communication is critical to gaining community ownership of this project.

Hold a Coalition Planning Meeting

Requirements for a Successful Meeting

Key requirements for a successful meeting include:

- An accessible location and time
- A good facilitator, if possible from outside the coalition, to help make sure all ideas are heard
- A good notetaker to record minutes, along with action steps, and distribute them to attendees

The following are possible tasks for the first meeting.

Goal Setting

The meeting should have a goal. One example would be: “This meeting will determine how community groups can collaborate on addressing local concerns associated with clinical trials.”

Team Building

Open the meeting with a team-building exercise. Pair people with someone they don’t know. Ask them to introduce themselves by telling the other person about groups they belong to, as well as a skill or talent they have. Ask people to introduce their partners by giving their names, where they’re from, groups they belong to, and a skill or talent. Comment on the number of groups mentioned, the various skills named, and how this is a beginning to building an effective coalition/partnership.

Information Overview

Be prepared to:

- Share clinical trials educational materials
- Discuss your goal in getting involved with advocacy
- Ask people to think about ways to spread the word

Brainstorming

In a brainstorming session, participants share their ideas or suggestions for solving a problem. Discussion of each point occurs after all ideas have been expressed. The atmosphere should be open and encouraging.

Use a newsprint pad and marker and ask for a volunteer “recorder.” In the groups:

1. Discuss community perspectives on barriers to clinical trials. How do they differ from the information presented? What other concerns do members of the community have? Focus discussion on barriers in the community, in institutions, and among potential participants.
2. Next, discuss possible solutions. Explain that this is a participatory goal-setting process. Discuss potential projects to let more people know about clinical trials.

Tip

You can use a buzz session in a coalition-building meeting as well as for a community meeting. If you use a buzz session instead of brainstorming, you may want to have the groups use worksheets to discuss the issues. The worksheets will help to determine community priorities for this project.

Mission Statement

Meeting attendees should work to develop a mission statement for the partnership. Examples of mission statements are:

- To determine the issues of importance related to clinical trials in our community, in order to develop a community-based advocacy initiative
- To work together to reduce the barriers to clinical trials in our community

The facilitator may need to further develop the statement and send it to attendees for comment at the second meeting.

Finding Other Partners

Brainstorm to decide on other groups to invite to the next meeting.

List the following organization types and examples on separate sheets of a newsprint pad:

- Service
- Religious
- Issue-oriented
- Social
- Educational
- Local or statewide councils and boards

When inviting groups to join the coalition, define the issue in a way that appeals to their self-interest.

Followup Steps

Participants should resolve the following before the meeting ends:

- How to continue communication among coalition members
- Who will facilitate future meetings (The facilitator should invite other organizations to join the coalition's next meeting. The group can elect someone to this position.)
- Who will coordinate an agenda for the next meeting (Committee assignments are one way to develop different parts of the agenda.)
- How additional input will be incorporated in the coalition's plans

To help you plan conducting community outreach and education, see the Plan for Action in the appendix.